Submission to the NDIS Regional Experience Inquiry

Consumers of Mental Health WA

23/02/2024

Consumers of
Mental Health WA

1. Preliminaries

About the Respondents

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues, psychological or emotional distress). We are a not-for-profit, systemic advocacy group independent from mental health services that exists to listen to, understand and act upon the voices of consumers. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

Request for Feedback

CoMHWA works to uphold the dignity and human rights of consumers, through providing advocacy in leading change with and for consumers. We appreciate notification of the outcomes of our submission to this consultation to understand and communicate the difference made through our work. Please provide feedback via the contact details on this submission's cover page.

Language

CoMHWA uses the term mental health consumer throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services. Other ways people may choose to describe themselves include "peer", "survivor", "person with a lived experience" and "expert by experience". Equally, Aboriginal and Torres Strait Islander people may have a preference for the term 'social and emotional wellbeing' as opposed to 'mental health'.

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify. As individuals we choose different ways to name and describe our experiences that may confirm or trouble ideas about 'mental illness'.

About the Inquiry : ‘NDIS participant experience in rural, regional and remote Australia’

Reproduced from the Terms of Reference

As part of the committee’s role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on the NDIS participant experience in rural, regional and remote Australia, with particular reference to:

> a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;
> b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;
> c. participants’ choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;
> d. the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS; and
> e. any other related matters.

Close Date: Friday 23rd of February 2024

Submissions to:

ndis.joint@aph.gov.au

2.Introduction

CoMHWA welcomes the opportunity to make a submission to the ‘NDIS participant experience in rural, regional and remote Australia’ Inquiry on behalf of our members, some of whom are NDIS participants living in regional and remote locations. Our regional and remote members often contact CoMHWA for advice and support in relation to either their NDIS Access Requests, or for further support managing their current Plan, which reveals a gap in the system for sufficient support and advocacy for NDIS applicants and Participants living regionally. The key themes that were clear in the responses we received from our members were:

- Difficult bureaucratic barriers and institutional knowledge are often needed to successfully pursue applications to, and further support for, the NDIS in regional locations.
- Longstanding lack of variety and stability of NDIS support services in regional areas, especially in relation to psychosocial disabilities.

- High regional turnover of NDIS staff makes consistent service and plan management a challenge for participants.
- Difficulties developing relationships with NDIA staff.
- Levels of support provided suffered from inconsistency both between, and within, services.
- The choice and control afforded to regional and remote NDIS participants was profoundly inhibited by the already extant issues of inadequate regional service options and delivery.
- While many members noted that NDIS support was life changing, most of these regional NDIS participants felt that they were lucky to have the capacity to learn how to successfully apply to the Scheme.

We base our submission on:

- An online survey open to the public and circulated to all CoMHWA members between the 22nd of January and the 9th of February 2024.
- Data recorded from our service provision streams, including our Service Navigation and NDIS Access programs.
- Ongoing consultation with consumers in Western Australia on joint priorities for an improved mental health system.
- Consumer representation in relevant settings, including but not limited to: Primary Health networks (WAPHA), WA regional equivalents of the Local Health Networks (regional mental health services under the WA Health Board structure), the Mental Health Commission and the health complaints agency, Health and Disability Services Complaints Office (HaDSCO).

3.Discussion and Recommendations

Regional barriers to NDIS Applications and Support Access

CoMHWA members who responded to our public survey expressed frustration with the current process to make Access Requests. While many of these responses echoed those of people living in Metropolitan areas, it should be emphasised that people living in regional, rural and remote areas face even more barriers to a timely and accessible application process given the fewer services available, longer waitlists and often higher cost associated with the services that do exist.

> *'Trying to arrange a functional assessment with an OT was nearly impossible.'*

Members noted that applying for Access to the Scheme required skills and capacity that many participants would not have, and that participants often had to rely on informal support from their families to assist with gathering evidence and submitting the application.

'I am a plan nominee for my adult son. We had to apply twice ... If I did not have the skills for this type of work, we would probably still not be approved.'

One respondent described their experience of needing to gain inside knowledge of the process in order for their application to be successful, which highlights how an inequitable amount of responsibility is placed on the person with disability to navigate a system that is complex and bureaucratic even for people who undertake this work as part of their professional roles:

'I spent months attaining all my reports through FOI, completing training for professionals on how to complete a successful NDIS access request. I then went through all my key professionals explained the wording that was required and the reports that would need to be added. This required a huge amount of intellectual capacity, knowledge and resilience from myself to which a high amount of people living with a disability would not have capacity to complete.'

Impact of Inadequate Regional Service Options and Delivery

Once participants have their Access Requests approved, barriers persist for people living in regional and remote areas to find quality services that meet their needs. Members report that in some regions, there is only one service provider available, and they may have lengthy waitlists or may not be the right fit for the Participant's needs; however, there are often no alternatives. Two respondents noted that finding a support coordinator was a challenge after an already lengthy and complex application process:

'I then spent a long time once successful finding a service that could coordinate my plan and services due to every service in the Wheatbelt stating they do not cover where I reside.'

'Difficult, first NDIS worker gave us a plan which wasn't useable and had to be redone, took a very long time. Then couldn't use the plan as I couldn't find a support coordinator to assist me that was taking new clients.'

One respondent described a positive experience with a support coordinator who happened to understand psychosocial disability, but noted this is often not the case as support coordinators are not provided with consistent, good quality training about psychosocial disability. They described their experience as 'lucky' and called for all coordinators and planners to receive specific training on all disability.

'I believe we have been lucky in the planners we have spoken to. I am concerned that "luck" should not play a part in the process. You get lucky if you talk to a planner who is familiar with, or has life experience with, a

> *psychosocial disability. If you got "unlucky" with the planner you received the outcome could be very different. Planners should be trained in whatever disability they are assessing.'*

For those whose plans did not provide support coordination, finding services on their own proved to be a difficult process to navigate, especially with the restrictions living in a smaller town. Once more, this respondent outlined how the process of finding support required higher capacity, knowledge, energy and time that many people with psychosocial disability do not always have.

> *'I had to find my own services and they were extremely limited… information from the start was not communicated in a way that I had the capacity to understand.'*

One respondent's story, when asked about the quality of their plan, highlighted the 'one size fits all' approach where NDIS plans are designed from a metropolitan perspective that does not consider the specific needs of regional, rural and remote communities and the heterogeneity of each location. This could perhaps indicate a need for the NDIA to become more flexible in plans and budgets to account for the need to travel further to available services.

> *'[The Plan was] Poor due to the [in]ability of NDIS to put a plan that could work in a regional town.'*

Impact of High Staff Turnover and Service Instability

Another point of concern for CoMHWA members responding to the survey was the impact that staff turnover has on the quality and continuity of support these members receive from both NDIS providers and administrators. The challenges of attracting and retaining regional staff are longstanding, however without a determined effort to incentivise the stability of regional staffing, consumers will continue to receive inadequate support. One member framed the impact of staff turnover as follows, contrasting a stable provider with those experiencing staff turnover:

> *'One provider has been amazing & stable. The rest is just a constant change in people, I've actually given up a bunch of therapies as a result because it was just a waste of time revisiting the same things with a new person each time.'*

The above response underscores the challenges consumers face when they are forced to build a new relationship and rapport with service providers. Consumers who have experienced trauma are particularly at risk in these circumstances, as the retelling of their story has the potential to retraumatise and make a recovery journey far more difficult. The challenge of retelling difficult personal stories was also emphasised in the following response to CoMHWA's survey, which revealed an associated issue of attracting experienced staff to regional services:

> *'Staff turnover is too high, need to start again with a new person each time. [There] also seem to be staff who aren't well trained or experienced.'*

This response shows that the quantity of available staff in the regional and remote areas is only a part of the problem—It is also critically important to ensure that there are enough experienced staff with contemporary training to help induct and guide newly recruited staff in these services about best practices and the unique challenges each region faces. Our members also told us stories of challenges emerging from inexperienced NDIS staff:

> *'…a well-meaning new support coordinator sat in front of our son with a laptop and ticked boxes - she had no idea how to communicate with psychosocial disability... I then arranged for a new support coordinator. I am concerned that not everyone has the skills to intervene and reorganise the service as I am fortunate to have.'*

This story demonstrates the hurdles that can be particularly difficult for regional and remote consumers, where the limited range of available staff means that there can be a suboptimal alignment between the needs of an NDIS Participant and the relevant experience of the person co-ordinating their care. While these barriers can be negotiated, it requires a level of systemic knowledge and consistent advocacy that many NDIS Participants may struggle to attain or have access to.

The Regional Illusion of Choice and Control

A key principle underscoring the NDIS is that participants have 'individual choice and control' over what services (within the parameters of their plan) they would like to use. However, for NDIS participants living regionally, their ability to exercise 'choice and control' over their support is often entirely undercut by the lack of available regional services. This deficit in regional NDIS services reflects both the absence of different services, as well as the capacity of the services that already serve regional participants. As one CoMHWA member wrote:

> *'Most service providers books are full. I can't find an appropriate support worker, adult OT or speech therapist.'*

In this instance, three key services that the member would benefit from are completely unavailable in their location. While they may, on paper, have the ability to choose between appropriate services, this choice is an illusion: If there are relevant services, they are often the only option, and subsequent access to this singular service is then contingent on the service having additional capacity. Having the autonomy to select the kind of support that is needed on the NDIS is thus completely contingent on a Participant's location. This problem is reflected in the following response from a CoMHWA member:

> *'When the plan was first approved my son lived in Narrogin and there was only one provider. He moved to Albany, more providers, which gave us greater choice and control.'*

The lack of choice and control faced by regional NDIS participants also makes it nearly impossible to find safe and appropriate services that can support the diverse backgrounds and needs of participants. As one CoMHWA member wrote:

> *'Just no availability of quality allied health or support workers in my area. Also no real consideration given to the additional challenges finding a LGBTIQA+ experienced and positive worker.'*

The difficulty outlined above in having access to support staff familiar with, and supportive of, LGBTQIA+ issues, shows an additional impact of the limited range of regional and remote services. Regions without a range of services to choose between will invariably fail to accommodate the diverse needs of consumers: for example, services that are culturally safe for First Nations Peoples, that understand the distinct challenges facing LGBTQIA+ consumers, or that have the knowledge to appropriately support people belonging to culturally and linguistically diverse populations.

CoMHWA members who have experienced regional NDIS access also highlighted how they had no choice or control over finding affordable services, due to the severely limited range of supports available. One member told us of the difficult costs faced when they required a service to visit them, noting that:

> *'Services charging huge amounts for travel, **if** they were even willing to come out here' (Emphasis added).*

NDIS Participants who live even a moderate distance from large regional hubs must either face the barrier of securing their own travel arrangements or face the high costs charged by services to make a visit. Moreover, many services do not offer to travel to participants, escalating the barriers to access and profound costs regional participants must overcome.

Barriers Experienced in NDIS Coordination

Many of our members expressed degrees of frustration about their experiences of NDIS coordination and the administration of their plans. These concerns centred around the availability of NDIA staff, and their region-specific knowledge of available services. The inconsistent support and coordination experienced by these members exacerbated an already stressful process, and relied on participants proactively taking steps to ensure that they did not fall between the cracks of the system. One CoMHWA member offered a particularly jarring story where they realised they would be without support from their planner for months:

> *‘In August 2023 I contacted by email the NDIS planner to advise a hospital stay as he had requested, but the email reply advised he was out of office until Jan. I believe the email should have been referred to another person so that the record could be amended, rather than an out of office email.’*

Beyond the concern over the availability of NDIA staff, other members discussed the lack of regionally specific knowledge about what suitable services were present in the area:

> *‘They just don’t have any knowledge of what services can provide support in my region… This needed my plan manager and myself to do a huge amount of research.’*

As in examples from previous sections, the lack of adequate support from the NDIA required the participant to go above and beyond their responsibilities, researching local services themselves alongside their plan manager. Many NDIS participants will not have the skills or capacity to cover this gap themselves, leading to delays in finding appropriate support and additional difficulties that are entirely inappropriate for people in the challenging process of getting the help that they need.

A final point of frustration expressed by CoMHWA’s members about engaging with the NDIA was the difficulties in establishing consistent contact with the Agency. The lack of consistency was highlighted in the following response to our survey:

> *‘[You] can't get on to a human, takes ages on the phone. [You get] Different answers from different staff.’*

The burden of navigating long waits via digital and telephone communication are exacerbated by the inconsistency of advice received by participants, who are often already engaged in the complicated process of application or reviews, with requirements that can be complex to understand and demonstrate. Without a consistent point of contact many consumers find themselves faced with additional barriers caused by miscommunication or unclear direction. One member felt that long distance communication with the NDIA was a problem in and of itself, writing that:

> *‘[They should] ensure NDIS comes out to rural towns to complete reviews, not just on Zoom.’*

While long distance communication should be available to participants that desire it, the NDIA would be better able to understand and navigate the unique circumstances of regional participants who might find it difficult to communicate why their current plan is not suitable or requires adjustment.

Conclusion

Currently, NDIS participants living in regional and remote locations are faced with an inadequate range of services to help them, as well as inconsistent support in the application to the NDIS and plan management. A large number of these issues are the direct result of the lack of regional support services and NDIS providers, which in turn forecloses the potential for participants to choose between services, or even to be able to receive the kind if support they require. Without focused, fully funded programs designed to address this regional/remote service gap and retain experienced staff for these NDIS services and administration, regional/remote NDIS participants will continue to be consigned to a second class of care. The importance of taking immediate steps to address the gap in regional NDIS support is underscored by the responses given from CoMHWA members about the profound and positive impact the NDIS has had in their lives—receiving support from the NDIS was described as 'life-changing', and we owe it to Australians living regionally and remotely to provide equitable access to the support they deserve.

Recommendation: The Government should take immediate action and commit to the goal of increasing the range and density of regional NDIS providers alongside a concerted effort to incentivise experienced staff to remain in these regional services. Both of these initiatives should be attached to benchmark future dates for evaluation and transparency.

Consumers of
Mental Health WA

12 / 275 Belmont Avenue, Cloverdale WA 6105
9258 8911 | admin@comhwa.org.au | ABN: 95 581 286 940

www.comhwa.org.au